Dementia Connection

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DATE: March 30, 2012

SUBJECT: Comments on NAPA from an Alzheimer's expert with 30 years of dementia experience

NAPA's outline is a **comprehensive masterpiece** which I am grateful for the opportunity to offer comments…I've waited decades for this!

I want to thank President Obama, for keeping the promise he made in response to my Town Hall question in Scranton PA during his initial campaign. My question to him was: "What do you plan to do about the Alzheimer's epidemic?"

Action 2.A.2: Encourage providers to pursue careers in geriatric specialties

Only 1% of physicians specialize in geriatrics; even fewer are experts in Alzheimer's and dementia. Less than 5% of nurse practitioners are certified as gerontological nurse practitioners. Similar statistics exist for psychiatrists who specialize in geriatrics or dementia care. We are about 13,000 geriatric physicians short now: the American Geriatrics Society estimated it will get worse: a 36,000 deficit of geriatric physicians by 2030. Is there hope?

The lack of Medicare reimbursement for comprehensive geriatric assessment, dementia assessments, family caregiver support, counseling and education have deterred young medical students from entering geriatrics. Geriatricians' salaries are considerably than physicians in sub-specialties. If the annual threat to cut Medicare continues, elders and Baby Boomers will suffer even further access to elder care specialists. If NAPA has any influence in this area, it is essential to have Alzheimer's experts for the dementia bubble ready to burst!

I, as a Gerontological Nurse Practitioner, taught family medicine residents Alzheimers and dementia care in nursing homes, assisted living facilities and on house calls between 1987-1999. Most medical students during the nineties were graduating with less than 10 hours of lectures specific to geriatrics: with no little or curriculum on Alzheimer's, dementia or geriatric pharmacology. Geriatric rotations were not common in many primary care residencies at that time. Even today, primary care provider attendance is lacking at continuing education programs on Alzheimer's disease. I suggest that NAPA offers funding for Alzheimer's CE programs to be offered by geriatric educators. I recommend at least four hours of annual mandatory CE for practicing physicians and other primary care providers on the following topics:

1. Geriatric Prescribing: This should include emphasis on the *Beers List of potentially inappropriate medications in elders*.
   Adverse drug events affect elders more than any other age group. Persons with Alzheimer's disease are at even greater risk for delirium due to their low levels of brain acetylcholine. There are over 6 million elders on one or more potentially inappropriate medications for elders. Adverse drug reactions in seniors are a leading cause of ER visits and hospitalizations; hence further driving up US health care costs. *Many providers remain uneducated re the Beers list.* This has been confirmed by many nurses who participated in my 600+ seminars in over 40 states).

2. Alzheimer's Disease (Late Onset and Early Onset) Vascular Dementia, Lewy Body Dementia, Parkinson's Dementia, and Frontotemporal Dementia:
   Primary health care providers need to be comfortable diagnosing and differentiating the major types of dementia, performing a dementia workup and treating Alzheimer's Disease/dementias using clinical guidelines. There are simply not enough dementia specialists for PCP's to refer to. The waiting times for families to see a dementia expert are much too long!

3. Behavioral and Psychological Symptoms of Dementia: All prescribers treating elders need to fully understand the risks of antipsychotic therapy, paradoxical effects of benzodiazepines in frail elders, and the non-pharmacological approaches to dementia behaviors. Providers should become familiar with the evidence-based research on these topics. This will enable them to help patients and their families learn the benefits of antidementia medications and the risks of antipsychotics and benzodiazepines in elders.

Action 2.A.4: Strengthen the direct-care workforce

With a rate of 50% turnover of nursing assistants and direct care staff in states like my own (PA), we need to make LTC a setting where staff remain, ensuring continuity for resident care. Direct care workers are at risk of physical injury and disability. Administrators face rising workman's compensation costs when behaviors of dementia re not optimally treated. Staffing issues, poor retention, burnout and lack of dementia education contribute.

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I request that national dementia experts who are entrepreneurs have opportunities to partner in business with governments and state agencies in educating the direct care workforce. I feel that at least 50% of training should be live; to allow staff to ask questions relevant to the patients they serve. Video and online learning can be a supplement, but should we not give the best to the staff that spend the most time with Alzheimer's residents? The #1 reason they resign is because they don't feel that they are respected. Honoring their efforts with live dementia education is an excellent strategy that will save money that is being spent on training a transitory workforce.

Many of us have been working in the community trenches of Alzheimer's care, outside of academic or research settings for decades and want to share our wealth of knowledge and experience. I've been educating nursing assistants, nurses and interdisciplinary staff for 12 years! The National Council for Certified Dementia Practitioners offers a full-day live curriculum that could lead national certification as a CDP: Certified Dementia Practitioner.

Dementia education should not be limited to nursing assistants. It should be available and funded for LPNs (who run most LTC units). Dementia research changes daily to weekly, so updates need to be shared with RN's, administrators, social workers, pharmacists, physical, occupational, recreational and speech therapists, social workers, and dieticians. Only through interdisciplinary education will senior communities be on the "same page" for best practices in long-term care, assisted living, CCRC's and home and hospice care.

I request that dementia education businesses that have clinical experience in dementia care be included in the force to strengthen the direct care workforce.

Action 2.A.5: Strengthen state aging workforces
HHS will coordinate with states to develop aging workforces that are AD-capable and culturally competent.
AoA will ask states to specify strategies to improve the AD-capability of the workforce.
I would request that state agencies will have grants and opportunities to partner with for-profits dementia education corporations, especially those that are reaching families currently though the power of social networking.

Strategy 2.B: Ensure timely and accurate diagnosis
I have been diagnosing Alzheimer's and dementia for 30 years. I still see nursing home residents, home care patients or nursing home residents who are not yet diagnosed until the moderate or late stage of Alzheimer's disease. I've met families in which loved ones were killed in auto accidents due to a driver with undiagnosed dementia, spouses who have been bankrupted by their husband's undiagnosed Alzheimer's disease. Part of the problem is family denial, apathy, fear, and helplessness. The remaining problem is that some health care providers lack knowledge of the dementia workup and evidence-based clinical guidelines for treatment. Continuing education is essential for providers: families need to be educated of the warning signs and know where to go for help.

Supporting people with Alzheimer's disease and their families and educating the public and providers.
This is HUGE. Families are starved for direction, information, support and resources. I have provided approximately 200 caregiver workshops in 40 states across the country. The lack of information on Alzheimer's disease causes family turmoil and division. I've seen cases of anger and elder abuse between family members who misinterpreted the personality changes of Alzheimer's as intentional behaviors. Many families have shared with me their frustrations with dementia care in the current health care setting. Seminars should be funded in the community, in senior centers, or in faith communities; where access is easy for stressed families and friends.

Action 1.E.3: Educate the public about the latest research findings
Translating research on dementias to professionals and the public has been the main focus of my dementia and geriatric education businesses for the past 12 years. I would request that HHS, VA, federal agencies, ADEAR will also partner with for-profit businesses who have been sharing Alzheimer's information in their businesses.

Action 2.C.1: Educate physicians and other healthcare providers about accessing long-term services and supports
Action 2.E.1: Evaluate the effectiveness of medical home models for people with AD Interdisciplinary collaboration needs to be initiated at the undergraduate level in the health sciences, including pre-med. I have taught graduate level geriatrics for 25 years. Evidence-based studies on quality of life, morbidity and mortality, functional state in elders consistently show that the interdisciplinary team approach offers better outcomes than standard medical care. Teams consistently outperform the hierarchical model of care. This should not be surprising, as Alzheimer's care and general geriatric care is functional, medical, psychological, pharmacological, social, spiritual, legal and financial. Alzheimer's care needs to be shared jointly, not "directed" by a single profession. Re the medical home concept, I would request that nurse practitioner with Alzheimer's or gerontological experience, be included as leaders in the Alzheimer's medical home model.

Action 3.B.2: Identify and disseminate best practices for caregiver assessment and referral through the long-term services and supports system
I would request that Medicare reimbursement codes be established for comprehensive caregiver assessments and that providers can choose the caregiver assessment instrument that works best for them; rather than be directed by a 3rd party. Suggested instruments are the The Zarit Burden Interview or the Modified Caregiver Strain Index (CSI). Reimbursement should be allowed for both initial diagnosis and counseling as well as ongoing caregiver assessment and support.

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Action 3.D.1: Educate legal professionals about working with people with Alzheimer's disease

I feel that for-profit Alzheimer's/dementia education corporations, non-profit dementia educators; Alzheimer's Association chapters should have the ability and financial incentives to educate attorneys. My opinion is that only attorneys who are CELAs (Certified Elder Law Attorneys) should be able to title themselves as elder care experts. There is a national examination and certification for other attorneys who are committed to the senior population who desire this certification.

Action 3.D.2: Monitor report and reduce inappropriate use of anti-psychotics in nursing homes

I have prescribed medications in LTC units over three decades. Over the past 20 years, OBRA had some impact on dementia antipsychotic use in nursing homes, but not as much as was hoped for. Despite a nearly doubled risk of mortality (1.7x) due to stroke, pneumonia, cardiovascular disease, antipsychotics are still routinely prescribed for behaviors related to dementia. Many prescribers are not aware that antipsychotic effectiveness for dementia was less than 20% effective in the CATIE study. Several studies revealed that staff dementia education was more effective than antipsychotic treatment for dementia behaviors. Funding should be available to educate prescribers regarding risks of antipsychotics for dementia. 88% of reimbursement claims submitted to Medicare for antipsychotic drugs prescribed for nursing home residents during a six-month review period (January to June 2007) were for residents diagnosed with dementia! So I applaud the recent work of Dan Levinson and the Office of Inspector General to reduce antipsychotic use for behaviors in dementia.

Please contact me if my 30 years in the "dementia trenches" will be of assistance to your remarkable action plan.

Respectfully submitted,

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